

Alport anti-GBM disease

This is a rare (probably less than 1 in 20) complication that can occur after a kidney transplant in patients with [Alport syndrome](#). It is very like a disease that can cause kidney failure out of the blue, [Goodpasture's \(anti-GBM\) disease](#), but the cause is different, and it can be more difficult to treat.

What causes it?

Normal kidneys contain the Alport protein that is often missing in people with Alport Syndrome. The immune system of someone with Alport Syndrome may identify the normal Alport protein as 'foreign' and attack it. Anti-rejection drugs may not be enough to prevent this reaction. Some degree of reaction is OK, but unlucky people get severe kidney disease.

Will it happen in another transplant?

Once you've had Alport anti-GBM it is common for it to happen again, and unfortunately it typically comes back even more strongly the second time. But some people don't get it back, they get away with it in a second transplant, and we don't yet know what makes the difference. It isn't necessarily as simple as waiting long enough, although most doctors would be very keen to leave a good long while, probably years.

When it is known that it is likely to happen, the medical team can be ready for it, but treatment may still be very difficult, and toxic, and may fail. It's a tough disease until we know more about how to stop it.

Will my brother / other son get it?

One person's bad luck doesn't mean your brother or other family member will get this complication. Alport anti-GBM probably never occurs in women with the most common type of Alport syndrome (X-linked, usually worse in men).

Can it be prevented?

There is a lot of research going on into how to make the body tolerant of 'slightly different' molecules like the Alport molecule. Much of this work is in transplantation, and about tissue type molecules, but some of it is in anti-GBM disease, and we are doing some of that in Edinburgh. None of these lines of

research have a revolutionary treatment ready to go yet, but these things always take long development, and there is real progress every year.

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